



Methods for Successful Follow-up of Elusive Urban Populations: An Ethnographic Approach with Homeless Men

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Abstract. *Public health is paying increasing attention to elusive urban populations such as the homeless, street drug users, and illegal immigrants. Yet, valid data on the health of these populations remain scarce; longitudinal research, in particular, has been hampered by poor follow-up rates. This paper reports on the follow-up methods used in two randomized clinical trials among one such population, namely, homeless men with mental illness. Each of the two trials achieved virtually complete follow-up over 18 months. The authors describe the ethnographic approach to follow-up used in these trials and elaborate its application to four components of the follow-up: training interviewers, tracking participants, administering the research office, and conducting assessments. The ethnographic follow-up method is adaptable to other studies and other settings, and may provide a replicable model for achieving high follow-up rates in urban epidemiologic studies.*

This paper describes an approach to longitudinal research that was developed for the follow-up of homeless men, and that could be adapted to assist with the follow-up of other hard-to-reach

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populations. The model entails an integration of ethnographic and epidemiologic approaches to follow-up research. In our studies of homeless men with mental illness, this approach resulted in virtually complete 18-month follow-up rates in each of two successive randomized clinical trials.¹⁻²

In recent decades, the follow-up of elusive populations has presented a major challenge to both behavioral and clinical research.³ The term, “elusive population” refers to groupings of people whose lifestyles do not conform to the societal mainstream^{4,5} and who, therefore, may be difficult to reach by traditional survey and follow-up methods.^{6,7} Homeless persons, illegal immigrants, injection drug users, and people with persistent mental illness are examples of such populations. Until recently, many social scientists and biomedical researchers considered these groups of marginal significance. However, now that conditions such as HIV and tuberculosis have spread to these populations, research has increasingly focused on them.⁸⁻¹¹

While the need for longitudinal studies of elusive populations is now widely recognized, such research has been handicapped by the inadequacy of conventional methods for follow-up in these populations. Looking at the evolution of follow-up studies, one can see that the need for specific tracking strategies developed over time. One of the earliest and now classic longitudinal studies, conducted by Terman,¹² spawned the development of a series of other pioneering longitudinal efforts in the late 1920s and early 1930s, which assessed various aspects of physical, mental, and personality development in children¹³ (e.g., Berkeley Growth Study, Fels Research Institute Project, Harvard Longitudinal Study). The participants in the majority of these studies were highly selected, white, middle-class volunteers, however, limiting challenges to follow-up. In 1946, a series of large British birth cohort studies¹⁴⁻¹⁹ began (e.g., MRC National Survey of Health and Development), and these were followed in the United States by birth cohort studies,²⁰⁻²² such as the Collaborative Perinatal Project. In these studies the samples were very large, the problems of sample attenuation and missing data became more prominent,

and the need for specific tracking strategies became apparent.¹³ With the introduction of epidemiologic studies using the cohort design, in which exposed and unexposed groups are compared on disease outcomes (e.g., the Framingham Study^{23,24}), the need for specific strategies to increase follow-up was further highlighted.

At the same time that the early cohort studies were initiated in the post-World War II era, clinical longitudinal studies²⁵ began to be extended to examine issues related to the onset, progression, and treatment of various conditions. An outstanding early example was Bleuler's²⁶ classic long-term follow-up of schizophrenia, but there were many others²⁷⁻²⁹; a more recent example is the MAC cohort for HIV/AIDS.³⁰ The widespread adoption of clinical trial methodology brought a qualitative change in the nature and use of follow-up studies and also amplified the intensity of follow-up methods.³¹⁻³³

The use of all these types of longitudinal studies in inner-city urban populations has been limited. There were, however, some notable exceptions. The Collaborative Perinatal Project sample in Baltimore was a predominantly inner-city, African-American population.²⁰ A large and representative cohort of youths in central Harlem has been followed by Brunswick *et al.*³⁴ since the 1960s. In regard to randomized clinical trials, the classic study of prenatal nutritional supplementation by Rush *et al.*³⁵ was conducted among women in Harlem. Yet, follow-up rates were sometimes modest and the methods used for follow-up have generally not been elaborated by the investigators.

Until the past decade, follow-up studies among inner-city *elusive* populations, such as the homeless mentally ill, who often are highly mobile, transient, or otherwise difficult to reach, were rare. In studies of homeless individuals with mental illness, attrition rates have been especially high—in large part due to failure of traditional tracking methods and to rejection of interview.³⁶⁻³⁹ This often results in poor retention rates, and thus, inconclusive results.⁴⁰⁻⁴² Thus, although mental health and social service agencies have developed a wide range of interventions to stabilize the health and social support systems of homeless individuals with

mental illness,^{43–45} evaluation of these innovative approaches has been extremely limited.

Faced with the need to achieve high follow-up rates in two successive randomized clinical trials in a population of homeless men with mental illness, we drew on basic principles of ethnography—the systematic study of a group’s culture—to help deepen our understanding of the environment in which the participants lived, their social networks, and their behavioral norms.^{46–50} This ultimately led to a set of principles and procedures that could be easily adapted across many studies of elusive populations. The context in which the studies took place is described below. This is followed by a description of the methodology used to train interviewers, track participants, run the research office, and conduct interviews—all of which contributed to an increased rate of follow-up in both studies.

Context: Participants, Setting, and Studies

Homeless men were recruited during temporary stays in a former Manhattan armory the size of a city block, which had served as a municipal men’s shelter for many years. Wall-to-wall cots had been set up on the National Guard drill floor, enough to shelter up to 1,000 men in a single room. Halfway through one of the research protocols, the number of men living in the shelter was substantially decreased by court order. Although this did not affect enrollment, it created a challenge for tracking study participants for follow-up assessment.

Participants for the two clinical trials were drawn from a subgroup of residents living in the shelter who were involved with an on-site Psychiatric Shelter Program (PSP).^{51,52} Approximately 75 men with severe psychiatric diagnoses, primarily psychotic disorders, were enrolled in the PSP.⁵³ The majority of these men were African-American or Latino, between the ages of 25 and 45 years, and diagnosed with schizophrenia or schizo-affective disorder. The majority of men in this study spent at least part of each day on the streets (i.e., panhandling or acquiring drugs and alcohol).

Many of the men exchanged money and drugs for sex in a nearby park.

The two studies used the follow-up method described in this paper. The first study was a randomized clinical trial to evaluate the “Critical Time Intervention” (CTI), which was designed to reduce recurrent homelessness by working with men during the time of transition from shelter living to community living.¹ Participants for this study were randomized into either the experimental or “standard care” group, and then placed in community housing. Each man in the experimental group was assigned a CTI worker for the first 9 months after community placement. Each man in the “standard care” group only had access to the shelter-based case worker for a 90-day period after community placement. The trial compared the number of nights spent homeless between the treatment groups over the year-and-a-half after placement. The primary outcome measure—nights homeless—was evaluated using a monthly interview,¹ which documented where a participant had spent every night during the month preceding each interview, according to the man’s self-report. A homeless night was defined as a night spent in the streets, a park, municipal shelter, subway train, or another public space. Ninety-six men participated, and residential status was obtained up to the 18th month of follow-up for 95 of the 96 men who participated (99%).

The second clinical trial assessed the effectiveness of a shelter-based intervention, “Sex, Games and Videotapes” (SexG), in reducing sexual transmission of the HIV virus.² Subjects for this study were randomized to receive either an 8-week experimental intervention or a 3-day control session. The trial compared sexual risk behaviors during an 18-month follow-up period. Subjects were interviewed each month, and asked about sexual behavior during the period since the last interview. These men were often more difficult to locate than the CTI sample because some of the men left the shelter before they could be placed. Despite this, 92 of the 97 participants (95%) were followed through the 18 months. Both clinical trials were rigorous and have been described in detail elsewhere.^{1,2,4,3}

Follow-up Methodology

Basic Principles

These interventions, and the clinical trials designed to assess them, involved the most intimate and sensitive areas of the men's lives, including substance use and sexual behavior. Rather than simply catalog 12 or 18 cross-sectional moments in the CTI and SexG studies respectively, our goal was to capture changes in vital areas in our participants' lives. In terms of collecting reliable data, we knew our success would depend first on our ability to develop a relationship of caring, respect, and mutual trust with the men. This required that the research team, particularly the interviewers, learn as much as possible about the participants' "ecology"—including the characteristics of their physical environment, the services, and institutions they used, and their network of social contacts. The interviewers also needed to be able to empathize with the participants' perceptions and feelings. Koegel has called this adopting an "insider's perspective."⁴⁶

In addition, each interviewer was assigned a caseload of participants to follow. This continuity over time helped the interviewer develop a relationship with the man's family, friends, and service providers, as well as with the man himself. For many of the participants, the research staff became a constant in the midst of dynamic change involving many areas of their lives. Whereas friends from the shelter, psychiatric hospital, or the streets might abruptly drop in or out of our participants' lives, the research team remained relatively intact. The office itself was a physical constant and a source of comfort for many of the men who remained undomiciled (see below).

In summary, trust and continuity are the principles we used to shape the different components of the follow-up phase of our studies. Below, we describe the four most critical components: training interviewers, tracking the participants, administering the research office, and conducting interviews. After a description of each component, a brief case study is presented.

1. *Training interviewers.* The project manager recruited interviewers who enjoyed working with mentally ill and homeless individuals. As is often true in academic settings, the interviewers were students: three were studying the field of anthropology and two were studying public health. Although they varied in age and life experience, all had “street smarts.” This gave them some insight into the men’s lives and helped them stay safe while tracking the men through potentially dangerous neighborhoods.

Part of adopting an insider’s perspective was understanding the fears and sensitivities of the community of which the study participant was a member. For many men and women living on the street, the police and other officials may be objects of fear, rather than sources of help or protection. Going to a hospital emergency room for an acute illness, for example, might well result in a prolonged involuntary psychiatric hospitalization. Sudden life changes such as this can lead a man to cut off all contact with friends and family.

Unlike non-psychiatric participants, the men sometimes had difficulty making the distinction between reality and the content of their delusions for purposes of the interview, and therefore required guidance from the interviewers. By entering into, or at least empathizing with, the lives of the participants, interviewers were better able to distinguish the answers reflecting a realistic appraisal of their life situation from responses based on delusion. This was particularly important when asking the men about their sexual encounters. Interviewers’ familiarity with the participants’ life situations also was valuable when attempting to track participants.

Case study A

A was a Puerto Rican man with a diagnosis of schizophrenia, but was high functioning when on appropriate medication. From the shelter staff, Interviewer W learned that A played a somewhat predatory role in the shelter, working with loan sharks in the community to victimize men in the shelter who borrowed money while waiting for their disability checks. A adamantly denied the

allegations, but some of the shelter victims lodged complaints. He was discharged to a tightly controlled transitional living community and was enrolled in the CTI study. He was interviewed by interviewer W once while he was there, but left shortly thereafter, leaving no forwarding address. Interviewer W knew what neighborhood A usually “hung out” in and had met some of his social contacts during a previous interview with A. Interviewer W scouted parks and subways in the area but could not locate A. He encountered some of A’s contacts, but everyone claimed not to have seen him and not to know where he was. After several visits to these various locations, one of the contacts suggested to interviewer W that he should stop asking about A. Apparently A had withheld some money from one or more loan sharks with whom he worked, and they were looking for him. We never were able to discover if A was successful in “disappearing,” or if he was “disappeared” by the men pursuing him, but realized it was potentially dangerous to keep inquiring.

2. *Tracking the participants.* We realized that conventional methods of tracking would not work well with our participants. Many of the men changed residences during the study period, and these moves sometimes involved a dramatic change from a highly structured group home to total autonomy in an apartment or on the streets. Some of the men who had been stabilized on psychotropic medications while in the shelter found it difficult to access medical care in the community and suffered a recurrence of psychotic symptoms after running out of medication. As they decompensated psychiatrically, they often found themselves in greater conflict with their families, friends, and service providers. This often led to recurrent homelessness. During these periods, the men were unlikely to show up for pre-arranged appointments, and they did not have residences where we could send a follow-up letter or have an interviewer visit. We needed to be both flexible and creative in our efforts to locate them.

The basis of our strategy for tracking men started while they were still in the shelter. The interviewers would spend time with the men in the shelter, often accompanying them when they went

out to learn the details of the men's daily activities. Interviewers consistently would collect information about the subject's family, community contacts, and social service providers. The clinical staff of PSP frequently assisted in communication with them. We drew on both this background information and the "insider's perspective" when trying to locate a subject. In addition, every successful interview deepened and updated our understanding of the men's lives. The knowledge gained made it easier to locate the men for the next scheduled follow-up interview.

Case study B

B was a Dominican in his late 20s who was diagnosed with schizophrenia. He was being seen in the PSP program and treated with Haldol. He had been in and out of the New York City shelter system for years and was known to be a heavy drug user. He was enrolled in the CTI study and underwent a baseline interview while in the shelter. Shortly thereafter, he abruptly left the shelter, presumably to go on a "drug run."

Interviewer X was assigned to B. X had spoken with B several times during the period he was in the shelter. B had proudly told interviewer X about an aunt living in the Bronx who he considered to be "the best cook who ever lived." B had lived with his aunt for varying periods, but she was unable to control his drug use and related behaviors and had told him to leave her house.

Interviewer X reasoned that it was likely that B would stay in the neighborhood around his aunt's house because he liked her cooking so much; Interviewer X was able to locate her. The aunt said that B was not staying with her, but that he had dropped by occasionally for a meal. She said she would let him know that X was looking for him.

Interviewer X had observed that B panhandled in front of the subway while he was at the Manhattan shelter and felt it was likely that the pattern would not change. He therefore located the two subways nearest to the aunt's house. The next morning, he found B panhandling downstairs at the first subway he visited. He

offered to buy him a donut and coffee, and they sat in a nearby park to complete the interview.

On the other hand, a number of the men spent time in highly structured institutions, such as hospitals, group homes, detoxification programs, and jails. While these facilities lent a form of stability to the men's lives, they were often obstacles to effective follow-up. For example, many of the facilities had inflexible rules about clients having contact with outside agencies. Interviewers had to spend considerable time and demonstrate a good deal of ingenuity and persistence to overcome these obstacles. For example, one of the men ended up in Attica State Prison, and our interviewer would take a 12-hour overnight bus ride, arriving at the prison gate in time for visiting hours. Because the interviewer was not allowed to bring pencil or paper, he would have to remember the participant's answers until he could leave and retrieve his notebook. He would then bus back to New York City, arriving the next morning.

3. *Running the research office.* It is less expensive, safer, and easier to have the men come to a research office for interviews, than to track and interview men on the streets. To encourage men to travel to our office, we adapted the concept of the *neighborhood store front*⁵⁵ to our research office, making it "user friendly" for both participants and staff. For many of the men, the entire research staff, not solely the interviewers, became valued companions. For example, office staff received phone calls from hospital social workers because study participants had listed them as the people to be contacted in case of emergency. The men felt welcomed and valued at the office, and for some of them, this was a stark contrast to the anonymity of their lives on the streets or in hotels.

Tokens or additional travel money were given to the men as an incentive for them to return. Along with other staff, at least one interviewer was in the office and available to conduct interviews every day. A detailed log book was maintained so that men calling in or dropping by either could be interviewed on the spot or reminded of a time to come in.

Case study C

C was an African-American man with a long history of schizo-affective disorder. He was stabilized on psychotropic medications while in PSP and enrolled in the CTI study. He met interviewer Y while he was still in the shelter. They got along extremely well and would talk about current events and television shows; C particularly liked Oprah Winfrey. He moved out of the shelter to his mother's apartment, but soon left and lived on the roof of a nearby building for a number of months before entering a transitional living community.

C never missed an appointment at the research office and sometimes stopped by simply to discuss something he had seen on TV or read. He arrived soaking wet for one of his last scheduled interviews. He did not have any money for transportation and had walked 70 city blocks from his transitional living community to the office in one of the worst rainstorms in the last 50 years. After he dried off, he wanted to know if any of us had seen Oprah interview Michael Jackson, and what we thought about the question of whether or not Michael Jackson was a virgin.

4. Conducting the interview. A frequent and painful part of the lives of many homeless, mentally ill men and women is being treated as non-persons. We were concerned that an overly structured questionnaire format would inadvertently make the study participants feel that way. If administered formally, a structured questionnaire conveys a sense of unequal power, with the interviewer explicitly scrutinizing and implicitly judging the behavior of the participant.

To avoid this dynamic, the interviews were held as conversations structured around a standardized format with coded responses and specified probes. Interviewers often started by asking what was on the participant's mind that day or by acknowledging some interaction from the last time the interviewer and participant had seen one another. The interview became a way for the participant to have a chance to talk about himself and his life to a person who was both empathic and knowledgeable. This often served to strengthen the men's sense of self and their interest and

commitment to the follow-up process. The interviewers were able to cover the various points of change in the men's lives necessary to score the instrument while maintaining the conversational format. Interviewers adopted the language and perspective of the participants to minimize communication barriers. This was particularly important when discussing sexual behaviors and drug or alcohol use. Interviewers exercised care to be non-judgmental and to guard the confidentiality of the information they were given.

We paid the participants a modest stipend (\$10) for their time. The money itself was certainly an incentive, but the men also received the explicit message that we valued their time and effort.

One potential problem with the development of a close relationship between interviewer and interviewee is the heightening of "social acceptability" bias—the participant tends to give answers that he believes will please, impress, or somehow aid the interviewer. Interviewers often dealt with this preemptively by distancing him or herself from the questionnaire *per se* and by telling the participant that the questions should just be answered quickly and honestly so that the two of them would have time to "hang out." This made the questionnaire something that was shared, but not defining of the relationship between them.

Case study D

Z was the interviewer assigned to D, an African-American man who left the shelter for a transitional living community. After a few weeks at this group home, D left abruptly, and neither staff nor other residents knew where he had gone. Interviewer Z knew that D had not yet received any benefits and therefore would be likely to be on the street rather than a hotel. He recalled that D always carried pornography magazines around the shelter and seemed knowledgeable about the seamier side of Times Square. Interviewer Z took a trip down to that area, carefully asking street people if they had seen D. One man thought he had seen D and gave Interviewer Z some directions. Interviewer Z found D lying in the doorway of a porno shop on 41st Street and 8th Avenue. D was both intoxicated and mildly paranoid. He recognized Inter-

viewer Z but would not speak with him. Instead, he began to walk away rapidly. Interviewer Z kept up with him, and D did not seem to mind. They walked across midtown Manhattan and finally stopped at a Burger King restaurant. Over hamburgers, D began to talk, and Interviewer Z was able to work some of the follow-up questions into the conversation. When they finished, D took Interviewer Z on a tour of his favorite spots, including the soup kitchen he frequented, the Meals on Wheels van he used, and the Citibank where he panhandled. As D spoke, Interviewer Z was able to get additional information on where D had spent the nights since the last interview. Interviewer Z finally escorted him to a church on 43rd Street where D often slept when the weather was bad.

Discussion

The validity of observational or intervention research depends critically upon adequate follow-up of subjects over time. For elusive populations, however, traditional follow-up methods are often not applicable. These methods presume that subjects can be accessed through mainstream social and service structures (home, work, family, health-care facilities) and further depend on subjects having the more typical motivations for continued participation. The strategies described in this paper are based on a recognition that the populations being studied have a different frame of reference and author a different reality. To integrate this understanding into study methodology, a simple principle has been implemented—the role of study subjects from hard-to-reach populations must be that of valuable confederate in the research. To achieve full benefit from this methodologic shift in frame of reference, the principle has been implemented at every level of study design, project development, and implementation.

To reduce attrition and increase rates of follow-up in difficult-to-reach populations such as the homeless mentally ill, it is especially important to anticipate and make concerted efforts, beginning with the initial contact.⁵⁵ With time, effort, commitment,

ingenuity, and perseverance, even difficult-to-reach study participants can be followed successfully.⁵⁶ However, because the strategies that we detail are labor-intensive, require highly motivated interviewers, and as a result may be more costly than traditional tracking efforts, we do not suggest that this approach is necessary for the follow-up of every population. With elusive populations, we believe that the more individualized strategies elaborated in this paper can contribute to the successful follow-up of even the most difficult-to-locate members of such groups.

To hold losses to a minimum, there are follow-up strategies that longitudinal researchers have identified, many of which were expanded on in this paper.^{57,58} In general, when a follow-up period is part of the study design rather than an afterthought, efforts can be planned to maintain the interest and motivation of the participants. For example, in an informal survey among longitudinal researchers in the field, conducted by Harway,⁵⁷ respondents indicated the need to “stress the personal touch” when inviting individuals to participate and at follow-up. Thus, as was demonstrated in this article, it is recommended that researchers personalize the request for participation rather than appealing to the altruistic motives of the individual. In addition, the collection of personal and detailed baseline data can provide clues to participants’ locations at later follow-up periods. As was demonstrated in our case examples, this can be vital to the successful follow-up of members of elusive populations. It is recommended that such data include detailed demographic information, identifying information on relatives or significant others, and detailed medical, psychiatric, and social histories, for example.^{17,59} To gain the maximum benefit from such information, it is particularly important to maintain detailed and complete records at each stage of data collection.⁵⁶ Between follow-up periods, personal contact also is important, as are the provision of incentives and actions^{35,59–61} to ease participants’ efforts (e.g., funding transportation to the interview site).

The virtually complete follow-up and data collection rates in the two studies described in this paper demonstrate that it is feasible

to conduct rigorous longitudinal studies in the homeless mentally ill. To achieve this result, we used many of the elements highlighted by Harway,⁵⁷ as well as those detailed by Wright, Allen, and Devine,⁵⁸ including frequent contacts, extensive familiarization with the subject's environment, material incentives, and flexibility in administering the interview. However, more fundamental than even these important techniques was the effort the research team put into making the men feel cared for and respected.

This was operationalized at each stage of the study follow-up period. Interviewers were selected who both enjoyed working with the homeless and mentally ill and respected the strengths that the men in the study developed through surviving on the streets of New York City. The interviewers were encouraged to learn as much as possible about each man's life and to become a defined part of it. This supplied continuity throughout the study period and often persisted long after the formal study was over. In addition, the better the interviewers understood the participant's habits, social networks, and psychology, the more likely it was that they could find the participant if he failed to show up for a scheduled interview.

Although there often can be a conflict between the formality of a structured interview instrument and the need to maintain a personal contact between interviewer and participant, we found that this could be overcome. Our interview instrument was standardized, but the interview itself was not. It usually was held in a conversational tone, and more personal topics were discussed both before and after administering the questionnaire proper. In this way, we maintained consistency and scientific rigor while fostering a fuller and more personal relationship with the study participants.

Finally, we also attempted to convey our respect by the way we dealt with the men when they visited the office: they were guests and shared in whatever beverages or snacks the staff had available. We were aware of security and safety issues for the staff and office space but balanced those concerns with a desire to create an

environment that was warm and welcoming. The relationships built were real, and many of the men still occasionally drop by.

Limitations

Although the results from the two clinical trials discussed above are robust, both studies are relatively small and draw on a very defined population: homeless men with severe mental illness living in a shelter at the time of enrollment. The fact that the men were initially in the shelter meant that we had an opportunity to get to know them before they returned to the community. Such an opportunity would not necessarily be available in a study of homeless living on the streets, or of the mentally ill living in the community. However, the principle of learning as much as possible about the participants' "ecology" remains valid and could be partially achieved through longer initial interviews at the time of enrollment in a study.

These studies were conducted at an academic center with relatively easy access to research assistants with a variety of interests and skills. Although three of our interviewers had some background in anthropology, this is not a prerequisite for working effectively with elusive groups. We believe that it was not the academic training, but rather the sincere interest in working with the homeless and mentally ill, that contributed to the success of the study.

Conclusions

Traditional follow-up techniques use scheduled appointments, telephone and mail notification, and, occasionally, home visitation. Although adequate for domiciled subjects with regulated lives, these methods often have proved inadequate for more elusive populations, such as the homeless, the mentally ill, substance abusers, and illegal immigrants. The conditions required to use an ethnographic approach to follow-up differ from those of a standard quantitative interview study. This approach is labor-intensive, uses highly motivated workers, and consequently may be more

expensive. Yet, in light of the high retention rates achieved in the studies reported in this paper, we believe it is worthwhile to consider using this approach for elusive populations when high retention is a critical requirement.

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